

ABSTRACT ~~(Structured)~~

Comment [JB1]: I would prefer the structured abstract

Background: The bodies of some transgender and intersex people have been mutilated and their minds subjected to immense distress. Their gender has often been determined by others. Loss of fertility used to be considered an inevitable consequence of treatment.

Comment [SR2]: one 'mutilation' remains in Abstract – all others modified

Objective: To review the ~~issue~~subject of preserving the reproductive potential of transgender and intersex people.

Methods: A narrative review based on a wide-ranging search of the literature in multiple disciplines.

Results: ~~There have been~~ major technological advances ~~have in~~ facilitat~~ed~~ion of reproduction for transgender and intersex people in the last few years. A majority of trans adults believe that fertility preservation should be offered to them. Deferment of surgery for intersex people is often best practice; gonadectomy in infancy closes off fertility options ~~and~~ ~~as well as~~ determin~~ing~~esing a gender they may later regret.

Conclusions: Transgender and intersex people should be able to consent to or decline treatment, especially radical surgery, themselves. Preservation of reproductive potential and sexual function ~~must~~should be given a high priority. ~~Individuals should be treat~~mented by multidisciplinary teams ~~can provide~~with a strong emphasis on mental health and wellbeing. Detailed information about options, an absence of any coercion and enough time are all needed in order to make complex, life-changing decisions.

ABSTRACT (Unstructured)

The bodies of some transgender and intersex people have been mutilated and their minds subjected to immense distress. Their gender has often been determined by others. People should be able to consent to or decline treatment, especially radical surgery, themselves. Loss of fertility used to be considered an inevitable consequence of treatment. Trans people should be offered the possibility of securing their reproductive potential before they transition. Many intersex individuals may safely have their surgery deferred until they are old enough to understand the issues. Preservation of reproductive potential and sexual function should be given a high priority. There have been technological advances in facilitation of reproduction for such people. Individuals should be treated by multidisciplinary teams with a strong emphasis on mental health and wellbeing. Detailed information about options, an absence of any coercion and enough time are all needed in order to make complex, life-changing decisions.

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KEYWORDS

Transgender; intersex; gender reassignment; gonadectomy; consent; reproduction

Word count

Abstract ~~(structured)~~ 19200 words

Main body of text ~~3474236~~ 3474236 words

Introduction

Transgender (trans) people are those for whom gender identity is incongruent with birth-assigned sex; they are also called 'gender-diverse' people. They are born with biological features belonging *unambiguously* to one gender but, later in life, identify and present in the world differently. People who [identify with their birth-assigned sex](#)~~are not transgender~~ are called cisgender.

Intersex people are those for whom development of chromosomal, gonadal or anatomical sex is atypical; they are also known as 'sex-diverse' people. Intersex has been added to the acronym first used by gay people which has gradually been extended to include all those who are non-heterosexual and non-cisgender: namely Lesbian, Gay, Bisexual, Transgender, Queer, Intersex and Asexual (LGBTQIA).

Not all trans people wish for or achieve a transition of gender. Those who experience discomfort or distress because of the mismatch between their biological sex and their gender identity (gender dysphoria) often need help. Those with a strong and persistent desire to live according to their preferred gender identity may change their clothing, hair and name accordingly but more usually will need medical assistance to change their appearance; treatment is in the form of hormonal therapy, often followed by gender reassignment surgery [\[1\]](#)~~y (Anonymous, 2011 #3667; Wylie, 2016 #3873)~~ the term sex

change is now out of favour. Male-to-female (MtF) transitions result in trans women and female-to-male (FtM) transitions in trans men.

Not all intersex people wish for or achieve a 'clear-cut' sex. Many have in the past been subjected to mutilated by radical genital surgery at a very young age. Unfortunately such surgery is often not cosmetically acceptable; it also leads later in life to pain, scarring, sexual problems [2, 3], urinary problems, depressive illness [4] and involuntary infertility.

Treatment for trans and intersex people has progressed enormously during the last fifty years. As with many developments in medicine, technical aspects have run ahead of the ethics; the psychology is complex and long-term treatment outcomes are not always those anticipated.

Transgender and intersex people are relevant to the topic of non-consensual sterilisation in that many of them~~such people have~~ undergone ne surgical interventions that removed d their gonads or distorted ed their anatomy to such an extent that reproductive function (and sometimes sexual function too) becomes impossible [5] ~~Creighton, 2001 #3874; Anonymous, 2014 #3876; Anonymous, 2014 #3876~~. While such people may be satisfied with the gender they have been assigned or chosen, they may regret that any potential for procreation has been lost. For trans people the issues have been the imposition of sterilisation in order for legal recognition of their gender identity to be granted and lack of opportunity to preserve their gametes; intersex people have suffered the consequences of decisions on surgery that were taken for them when they were very young.

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The ~~is~~ ~~authors~~ ~~article~~ ~~have~~ ~~does~~ not attempt~~ed~~ to summarise the complex and wide-ranging subject of transgender ~~r~~ [1] ~~r~~ ~~{5}~~ and intersex [6] medicine and surgery. ~~They~~ ~~it~~ examines problems that transgender and intersex people encounter and suggests ethical principles that should underpin their care. Although there are many distinctions between trans and intersex people, there is an overlap in the area of their future fertility and the medical expertise necessary to care for both groups in this respect [7].

Method

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The authors ~~have~~ conducted a literature search of all material freely available on the subject for the years 2000 to 2017 in English, French and Dutch languages. These sources included journals in various disciplines, books, theses, government publications, publications by non-governmental organisations, articles in the lay press and information from reliable internet sources.

Results:

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~~Background to transgender issues~~Transgender Issues

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Lili Elbe (portrayed in the film *The Danish Girl* [8]) underwent one of the first gender transitions. She had gender reassignment surgery (MtF) in Germany in 1930 and 1931; such treatment was highly experimental at the time. A series of operations included orchidectomy, penectomy, fashioning a vagina and transplantation of uterus and ovary. She died of complications of the surgery (anti-rejection drugs were not in use until the 1960s).

The first publicised gender reassignment surgery (MtF) was done in Denmark in 1952 on Christine Jorgensen, a former American soldier [9]. The first gender identity clinic was established at the Johns Hopkins Hospital, in Baltimore MD, in 1966. The endocrinologist Harry Benjamin was a pioneer in the field. Now, hormone therapy and surgical reassignment have become mainstream and have gained respectability [10].

[It is estimated that as many as 0.6% of the population may have a gender variant identity \[11\]. Hormone therapy and gender-affirming surgery are correlated with an improved quality of life \[1\]. Genital reconstruction surgery is the last stage in transition for those who cannot accept their gender dysphoria.](#)

A recent development is the use of 'puberty blockers' [12, 13]. Children who exhibit signs of gender dysphoria can be treated with gonadotrophin-releasing hormone agonists (GnRH-a) to delay puberty and give individuals more time to consolidate their gender identity. However, compromising future fertility is an adverse effect which needs detailed discussion before this treatment is [entered into](#)applied.

Nowadays, gender reassignment has become a commercial industry. The greatest number of operations are done in Thailand [14], followed by Iran. Rather like Hungary and Poland offer good-value dentistry and South Africa plastic surgery to foreigners, India supplies affordable gender reassignment surgery to medical tourists [15].

Not all trans people choose to have hormonal treatment or surgery. Medical certification requirements of having been rendered sterile in order to change gender on official documents interferes with a trans person's right to bodily integrity.

▲ *Fertility in transgender people*

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One of the historical reasons behind mandatory sterilisation laws for those changing gender is society's need for legal certainty [11]. There is a concern that men giving birth or women producing sperm destabilises family law systems and confuses the progeny. Nevertheless, European law (see below) now dictates that those undergoing transition retain the choice as to whether or not their reproductive organs are modified.

~~Some trans people may have had/been responsible for children before they transition; others will not.~~ Loss of fertility was once considered a *sine qua non* of gender transition; the 'price you pay' if you will [7]. Transgender individuals and their healthcare teams now

recognise that options for preserving reproductive potential exist. Half of trans women and trans men wish to have children [16]. A majority of trans adults believe that fertility preservation should be discussed with, and offered to, them [7, 16]. Low uptake of fertility preservation [by](#) transgender youth needs further exploration [17].

The use of GnRH-a prevents the development of distressing secondary sexual characteristics but also suspends germ cell maturation. Oestrogen used by trans women results in impaired spermatogenesis. Testosterone used by trans men suppresses the ovaries. Because the dosage and duration of these gender-affirming hormones without irreversible effects are not known, the implications on fertility must be discussed before their initiation. Those deciding on hormone therapy or gonadectomy, may opt for cryopreservation of gametes beforehand [7, 16, 18, 19, 20]. For those trans men wanting a 'full' FtM transition, a hysterectomy and bilateral salpingo-oophorectomy, amounting to the removal of all internal genital organs, is needed.

~~Background to~~ *intersex issues*

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Crude biological terminology such as hermaphroditism was used before the term disorders of sex development (DSD) was adopted by the medical profession. Hermaphrodite (from Hermes and Aphrodite in Greek mythology) implies being fully male *and* fully female which is physiologically impossible. The term pseudohermaphroditism was also used to indicate

the possession of primary sex characteristics of one sex (based on the type of gonad) and the secondary sex characteristics of the other [21]. Intersex people themselves firmly reject the term DSD as 'pathologising' terminology [4, 22]. Intersex continues to be the term preferred by the community living with the condition.

Intersex people are a disparate group. They have a bewildering array of medical conditions comprising at least 40 different entities [23]: from congenital adrenal hyperplasia, androgen insensitivity syndromes, gonadal dysgenesis, various enzyme deficiencies to chromosomal variants such as Klinefelter syndrome and Turner syndrome. Intersex may be apparent at birth or, much less commonly, may reveal itself at puberty. The currently recommended clinical approach differs completely from what it was only two decades ago. Decisions on [sexgender](#) of rearing must not be rushed into [22].

Estimates vary, but most likely about 0.5 - 2 per 1,000 babies born are intersex [4, 24]. 'Intersex' describes a biological variation in members of a species that means they cannot be comprehensively described by the labels 'male' or 'female' [22]. Intersexuality represents a range of genetic, chromosomal and hormonal circumstances. Intersex may be evident from genotype: people may have variations in their genes and chromosomes other than the 46,XX and 46,XY karyotypes that define typical female and male sex, respectively. There may be variations in phenotype: the observable sex characteristics of the body may differ from those of a typical male or female. The circumstances that lead to someone being intersex include unusual combinations of X or Y chromosomes, anatomical variations in genitals that are ambiguous at birth, or subsequently, and variations in hormone production at different stages in development [22].

In the past, the expectation was that infants should be assigned a binary gender (female *or* male) - and would adhere to this [25]. Also, there is pressure for ambiguous genitalia to be refashioned so as to appear 'normal' and for medical decisions about allocation to be made in infancy. Parents are put in the invidious position of having to give consent for their child to undergo surgery, often without apprehending all the facts and with their child's condition ~~often~~ under a veil of secrecy. Parents of intersex children are ~~commonly~~~~often~~ anxious, shocked and confused when confronted with the diagnosis and proposed management. Their key motivation is the desire to protect their child from negative social and emotional outcomes and from stigmatisation; this may not always tally with their child's best interests [24].

Attempts at 'corrective' surgery for intersex began in the 1920s. Initially, not enough was understood about the genetic and endocrine complexity, so that inappropriate interventions were made based on the examination of the external genitalia. Early genital surgery was initially favoured because of [26]:

- less emotional trauma if done before the starting point for childhood amnesia (probably somewhere between the ages of four and seven years)
- the assumption that firm gender identity would be best supported by genitalia that looks congruent with the adopted gender
- parental preference for an early solution to the problem
- excellent wound healing in infancy

During the 1970s and 1980s there was a simplistic acceptance in medical circles that genitalia should be fashioned that would permit normal penetrative sexual intercourse. There was also a tendency to reassign genetically-male individuals with a small or absent penis as females and undertake feminising genitoplasty [2, 27].

The tragic Canadian case of David Reimer received wide publicity [28]. Reimer was reassigned as a female following destruction of his penis in a circumcision operation in 1966. He had an orchidectomy at age 22 months. At age 14 his parents told Reimer the truth about his operations and he reassumed a male gender identity. He ~~got~~ married at the age of 25 ~~but~~ ~~He~~ had psychological problems later in life and ultimately committed suicide. A somewhat similar British case was that of Joe Holliday who was raised from the age of one to the age of 25 years as a female due to a congenital anomaly including an absent penis [29]. Holliday suffered many years of mental anguish living as a female.

In the 1990s advocacy groups protested about past treatments. The medical profession had little data on which to base ~~any~~ guidelines and a complete lack of information on long-term outcomes. A consensus meeting in Chicago in 2005 [30] resulted in some clarity but the lack of evidence hampered production of any definitive recommendations. The Chicago consensus did not directly address fertility potential. Since then, there have been some further studies, but with an undue emphasis on surgical techniques and an absence of enquiry into patient experiences [2]. However, a 2016 update did acknowledge the importance of psychosocial and psychosexual wellbeing and emphasised the value of peer support [31]. Parents of intersex people find contact with families in the same situation and with support groups valuable [32].

Two types of genital surgery have been developed to manage intersex people (often while still infants or children): cosmetic 'normalisation' and interventions to circumvent potentially elevated cancer risk (hidden gonads may be liable to carcinogenesis - type-II germ cell tumours [30]). Early gonadectomy, unfortunately, adversely affects bone maturation and body development [27]. German data show that 64% of intersex people undergo gonadectomy [4]. Extreme caution is needed when subjecting individuals with intersex to radical surgery ~~is being considered~~ as there is such a major shortfall in information about long-term outcomes [30]. It is recommended that valid consent is ensured in connection with medical and surgical treatments for intersex people; ideally, except in cases of life-threatening urgency, irreversible invasive medical interventions ought to be postponed until children are sufficiently mature to make their own decisions about treatment [33]. ~~It has now become apparent that deferment of surgery is often best.~~

Protection of children from ill-considered early surgery can be brought about by safeguarding policies and laws [25]. Gender dysphoria can occur when an individual develops a gender identity discordant with the sex assigned as an infant.

Many intersex people maintain secrecy as the condition is so stigmatised. But in January 2017, the Belgian fashion model Hanne Gaby Odiele came out publicly in *Vogue* magazine at the age of 28 [34]; this openness helps improve public understanding and breaks down stigma.

Some intersex people are naturally fertile. Others ~~are not~~may be infertile; however, their gonads — whether ovaries or testes - are capable of producing hormones. There are also some intersex people who, while not capable of unassisted reproduction, may be able to have children with medical support, either with currently available assisted reproductive technologies (ART) [35] or as new scientific advances occur. Those with functioning ovaries but no uterus may opt for surrogacy [2]. Those with a uterus but no functioning ovaries may consider oocyte donation.

Intersex people are at risk of potential infertility because of the following:

- abnormal gonadal development
- gonadectomy for malignancy risk
- abnormal hormonal function
- discordance between gonadal type and gender identity

Success in achieving biological offspring in males has most frequently been reported following testicular sperm extraction ~~(TESE)~~ and/or intracytoplasmic sperm injection [7]. However, in a six-country European study, only 3.5% of intersex people had conceived without ART; ~~whereas, a further~~ 7% had conceived with use of such methods ~~ART~~ [35].

Comment [SR4]: defined on previous page

In 2003 in *Van Kück v Germany*, the European Court of Human Rights (ECtHR) ruled in favour of a trans woman whose insurance company had refused to cover her gender reassignment surgery [36]. This judgment went against the German domestic courts, including an appeal.

Christiane Völling was the first person known to have successfully sued her doctor in relation to non-consensual sex reassignment. Völling argued in the German courts that she was not informed about her condition or her options and so consent was invalid. She also maintained that with appropriate treatment she could have lived the life of a woman, including full female sexuality and the ability to procreate. She had ambiguous genitalia and was initially brought up as a male, but at the age of 14, during an appendicectomy, it was noticed she had a uterus, tubes and ovaries in her pelvis. At age 18 she was found to have an [46, XX karyotype](#) and had a hysterectomy and bilateral salpingo-oophorectomy. Later on, she transitioned to live as a woman. She was awarded €100,000 by the Regional Court of Cologne in 2011, 30 years after the removal of her reproductive organs [37].

In the 2015 case of *YY v Turkey* the ECtHR ruled that Turkey had breached respect for the individual's private and family life by refusing to authorise FtM gender reassignment surgery on the grounds that YY was not permanently unable to procreate[36]. The judgment will hopefully ensure that individuals who medically transition need only access treatments that are both necessary and desired [38].

In April 2017, in *AP, Garçon & Nicot v France* the ECtHR ruled [in a landmark judgment](#) that the requirement to undergo sterilisation or treatment involving a very high probability of sterility in order to change entries on birth certificates was in breach of the right to respect for private and family life [\[11\]](#).^e {Cannoot, 2017 #3818; Dunne, 2017 #3871}.^f This means that the [1922](#) European countries [\[38\]](#) in which sterilisation is still mandatory will have to swiftly put an end to this practice.

Reparations

Transgender Swedes had to undergo sterilisation before they could legally change their gender between 1972 and 2013. In March 2017, the Swedish government announced that it would grant compensation to an estimated 800 trans people in the sum of 225,000 Swedish Krona (about €23,600) each [39]. However, no apology was forthcoming.

Progressive laws

Under progressive laws, individuals have the right to determine their own gender identity without first having to undergo medical tests, forced sterilisation, a forced divorce or a

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mental health diagnosis [40]. In some countries normalising surgery on intersex babies is prohibited and parents can postpone the entry of gender on the child's birth certificate until the gender identity is determined. In the last decade or so, numerous countries have modified their law accordingly, giving more respect for bodily integrity and physical autonomy; these include Argentina, Austria, [Belgium](#), Bolivia, Chile, Colombia, Denmark, Ecuador, France, Germany, Greece, [Hungary](#), Ireland, Italy, Malta, Norway, Portugal, Sweden, Turkey, Ukraine, UK, Uruguay and Vietnam [5, 40, 41].

However, a considerable number of countries still require a mental disorder diagnosis and/or gender reassignment surgery (effectively sterilisation) for legal gender recognition. [Two countries have recently rejected proposals to remove mandatory infertility provision: Poland in 2015 \[42\] and Finland decided against a progressive law in August 2017 \[43\].](#)

Some jurisdictions allow for three data-recording options for biological sex and/or gender information: M (male), F (female) and X (indeterminate/intersex/unspecified). They also allow for change from one category to another. However, a third category can lead to 'forced outings' and pressure on parents of intersex children to decide in favour of one sex.

Modern management principles

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[All trans and intersex people deserve respect and to be treated according to the Yogyakarta principles](#) [44]. The World Professional Association for Transgender Health recommends that genital surgery for trans people should not be carried out until they have ~~both~~:

- reached the legal age of majority in their country of residence and
- lived continuously for at least 12 months in the gender role that is congruent with their gender identity [18]

The Halifax resolution includes reference to preserving reproductive potential, preserving capacity for satisfying sexual relations and leaving options open for the future [45]. The Council of Europe has called for the right of intersex people to opt *not* to undergo gender reassignment surgery [4]. The following principles for management of intersex have been agreed among medical experts [22, 30]:

- Gender assignment must be avoided until there has been expert evaluation in neonates
- Evaluation and long-term management must be carried out in a centre with an experienced multidisciplinary team
- All individuals should receive gender assignment
- Open communication with patients and families is essential, and participation in decision-making is encouraged
- Patient and family concerns should be respected and addressed in strict confidence

Comment [SR5]: Difficult to tone wording down as a direct citation from two references given

The authors would point out that the last three bullet points above could be considered paternalistic; they are not fully in keeping with allowing the individuals concerned to decide themselves on their gender. They give undue precedence to the family and the treating healthcare professionals; they allow the performance of gender reassignment surgery at any age.

There is a consensus that intersex people ~~should~~ are best treated by multidisciplinary teams using guidelines, within a human rights framework [24, 27]. Preserving the potential for fertility is a core principle guiding multidisciplinary teams [46]. Nevertheless, there is still concern that some surgeons continue the 'old' way without treating people with intersex as individuals, without offering psychosocial support and not deferring most surgery until the individuals themselves can give consent [47].

Conclusions

Comment [SR6]: Five 'shoulds' have been taken out!

Trans people who decide to undergo a transition which includes genital surgery are no longer ~~are~~ obliged to sacrifice their reproductive potential. There are ever-increasing options for preservation of gametes; trans people need to know about these options and to be given the opportunity to fully consider them before gonadectomy is carried out.

Although technically possible soon after birth, 'normalisation' of intersex genitalia too soon can have adverse outcomes. Not only may individuals later not identify with the sex they have been assigned, but they may have had fertility options denied to them.

Human rights bodies have recommended the revision of laws to remove any requirements for sterilisation of trans people [who wish to have their gender change recognised](#); this is now incorporated into European law. [It has become apparent that deferment of surgery is often best for intersex people.](#) ~~It is also recommended that valid consent should be ensured in connection with medical and surgical treatments for intersex people; ideally, except in cases of life-threatening urgency, irreversible invasive medical interventions should be postponed until children are sufficiently mature to make their own decisions about treatment [47].~~

~~All trans and intersex people should be respected and treated according to the Yogyakarta principles[48]. Attempts should be made to p~~preservation ~~of their~~ reproductive potential and sexual function [is a priority](#), while minimising health and psychosocial risks and leaving options open for the future ~~[24, 44]. They should be protected by L~~legislative and administrative measures [can be introduced to protect them](#) from any harmful medical practices. Those undergoing treatment are entitled to competent, individualised, non-discriminatory treatment, care and support.

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